TOFACITINIB is used to treat rheumatoid arthritis and psoriatic arthritis
Introduction

Tofacitinib is a drug that can help prevent your condition causing damage to your body. You can discuss the benefits and risks of taking tofacitinib with healthcare professionals before you start treatment, so you’re able to make an informed decision.

What is tofacitinib and how is it used?

Tofacitinib (trade name Xeljanz) is a type of drug known as a Janus kinase (JAK) inhibitor. It works by blocking the action of Janus kinase enzymes, which are involved in the inflammation that causes the symptoms such as pain and joint swelling in rheumatoid arthritis and psoriatic arthritis.

Tofacitinib is a long-term treatment. Most people who benefit from this treatment will notice an improvement within a few weeks of starting treatment, but further improvements may be seen over the first six months of treatment.

Tofacitinib can be prescribed by a rheumatologist for adults with rheumatoid arthritis (roo-ma-toy-d arth-ri-tis) or psoriatic arthritis (saw-ree-at-ic arth-ri-tis). It can be used alone or with other disease-modifying drugs such as methotrexate.

Tofacitinib won’t be started if you haven’t tried other treatments appropriate for your condition first.

Is tofacitinib suitable for me?

Your doctor may decide not to prescribe this treatment if you’re pregnant, planning to try for a baby, or breastfeeding or if you have or have had:

• an infection, or repeated or serious previous infections
• shingles
• disease of the lungs, liver or kidneys
• heart problems, high blood pressure or high cholesterol
• stomach ulcers
• cancer

Tofacitinib contains lactose, a type of sugar found in dairy products. You should tell your specialist if you have a lactose intolerance that means you can’t digest lactose normally.

You’ll probably have blood tests before treatment starts to assess your condition and to check whether the drug is suitable for you.

Your doctor will need to check if you’ve previously been exposed to tuberculosis (TB). Even if you don’t have symptoms, the bacteria that cause TB may still be present in the body and you may need a course of treatment to deal with this before starting tofacitinib.

It’s recommended that you should be checked for previous hepatitis infection before starting tofacitinib. It’s not yet known whether tofacitinib might increase the risk of hepatitis coming back, but your doctor may suggest regular checks as a precaution.

If you’re taking other drugs alongside your tofacitinib (such as methotrexate) you’ll still need regular blood tests for these.

Your rheumatology team will also monitor your immune system once you start treatment. If your red or white blood cell count gets too low, your treatment may be stopped until it improves.

You may have to be monitored for other conditions as well, for example if you have liver problems or high cholesterol. Tofacitinib raises cholesterol levels in some people.
**When and how do I take tofacitinib?**

Tofacitinib is taken as tablets that can be taken with or without food. The usual dose is two tablets a day – one in the morning and one in the evening. However, in some circumstances, your doctor may suggest taking just one tablet a day.

If you take more than the recommended dose by mistake, contact your doctor immediately. If you miss a dose, carry on with the usual dose the next day – do not double it.

If you haven’t noticed any improvement in your symptoms after six months, discuss it with your doctor, who may decide to stop the tofacitinib treatment.

Because it’s a long-term treatment, it’s important to keep taking tofacitinib, unless you have severe side effects:

- even if it doesn’t seem to be working at first
- even when your symptoms improve (to help keep your arthritis under control).

**Possible risks and side effects**

Like any medicine, tofacitinib can cause side effects but many people won’t have any problems. You should speak to your rheumatology team if you have any side effects.

Janus kinase inhibitors such as tofacitinib are a fairly new group of medicines. Because of this, we know less about the risk of longer-term side effects than we do for other medicines.

The most common side effects are headaches and diarrhoea. These aren’t usually serious and should soon pass. Feeling sick is fairly common, especially when you first start taking tofacitinib.
Because tofacitinib affects your immune system, it can make you more likely to pick up infections. These aren’t usually serious and include throat, nose and chest infections, cold sores, urinary tract infections and stomach upsets. Some people may have more serious infections including skin infections (cellulitis) and shingles.

Tell your rheumatology team straight away if you develop any signs of infection such as a sore throat or persistent cough, fever or chills, or any other new symptoms that concern you. If any of these symptoms are severe, you should stop taking tofacitinib and see your doctor straight away.

You should also speak to your rheumatology team if you develop chickenpox or shingles or come into contact with someone who has chickenpox or shingles. You may need antiviral treatment, and you may need to stop taking tofacitinib until you’re better.

Some people who take tofacitinib may have a reduced white blood cell count, raised cholesterol or raised levels of liver enzymes. These problems are usually mild, but your rheumatology team will arrange regular blood checks while you are taking tofacitinib as a precaution. If your red or white blood cell count gets too low, your treatment may be stopped until it improves.

It is possible that tofacitinib may increase the risk of blood clots (deep vein thrombosis and pulmonary embolism). The risk is likely to be greater if you’ve had either of these before. Seek urgent medical care if you develop swelling of the legs or breathlessness.
Tofacitinib can sometimes cause stomach or bowel problems. These are more common in people who also take NSAIDs or corticosteroids. You should also tell your doctor straight away if you notice any signs of stomach or abdominal problems, such as pain, a change in bowel habits or passing blood.

Rarely, tofacitinib can cause an allergic reaction with sudden swelling, a rash or breathlessness. If you do develop these symptoms, or any other severe symptoms while taking tofacitinib, you should seek medical advice straight away.

**Tips to reduce your risk of infection**

- Try to avoid close contact with people you know have an infection.
- Wash your hands regularly and carry around a small bottle of antibacterial hand gel.
- Keep your mouth clean by brushing your teeth regularly.
- Stop smoking if you’re a smoker.
- Make sure your food is stored and prepared properly.
- Try to keep your house clean and hygienic, especially the kitchen, bathrooms and toilets.

**Taking other medicines**

You’ll probably be taking methotrexate as well as tofacitinib. However, some drugs may interact with tofacitinib. Check with your doctor before starting any new medicines, especially if you’re taking medicines to treat bacterial or fungal infections. And remember to mention you’re on tofacitinib if you’re treated by anyone other than your usual rheumatology team.
You may be more likely to develop a serious infection if you’re taking tofacitinib alongside steroid treatments or other drugs that affect the immune system.

You can carry on taking non-steroidal anti-inflammatory drugs (NSAIDs) or painkillers, if needed, unless your doctor advises otherwise.

Don’t take over-the-counter or herbal medicines without discussing it first with your rheumatology team.

**Vaccinations**

It’s best to discuss vaccinations, including any you may need if you’re planning to travel abroad, with your rheumatology team. If possible, it’s best to have any vaccinations you may need before starting tofacitinib.

Live vaccines aren’t usually recommended once you’ve started tofacitinib. These include measles, mumps and rubella (MMR), tuberculosis (BCG), yellow fever and shingles.

Pneumococcal (new-mow-cok-al) vaccines, which help to protect against pneumonia, and yearly flu vaccines – except the nasal flu vaccine – are fine and are usually recommended.

**Having an operation**

If you’re thinking about having surgery, talk this over with your specialists. They may advise you to stop tofacitinib for a time before and after surgery.
**Alcohol**

There’s no known interaction between tofacitinib and alcohol. However, if you’re also taking methotrexate, you should keep well within the recommended limits of no more than 14 units of alcohol per week for adults. This is because methotrexate and alcohol can interact with each other and affect your liver.

In some circumstances your doctor may advise lower limits.

**Fertility, pregnancy and breastfeeding**

At present, we know very little about the effects of tofacitinib in pregnancy. To be on the safe side, tofacitinib isn’t recommended for women who are pregnant or planning a pregnancy. Women who could become pregnant should use effective contraception while being treated with tofacitinib and for at least four weeks after stopping the treatment.

It’s not yet known whether tofacitinib passes into human breast milk, so breastfeeding isn’t generally recommended if you’re on tofacitinib.

There’s currently no information on whether tofacitinib might affect male or female fertility.
This leaflet is a guide to tofacitinib, its benefits and potential side effects. If there's anything else you’d like to know about this drug, just ask the healthcare professionals in charge of your care.

Thank you!

A team of people helped us create this booklet. We would like to thank Neil Snowden, Ben Thompson, Sandra Robinson and Alison Bayliss for helping us with reviewing this booklet.

We would also like to give a special thank you to the people who shared their opinions and thoughts on the booklet. Your contributions make sure the information we provide is relevant and suitable for everyone.